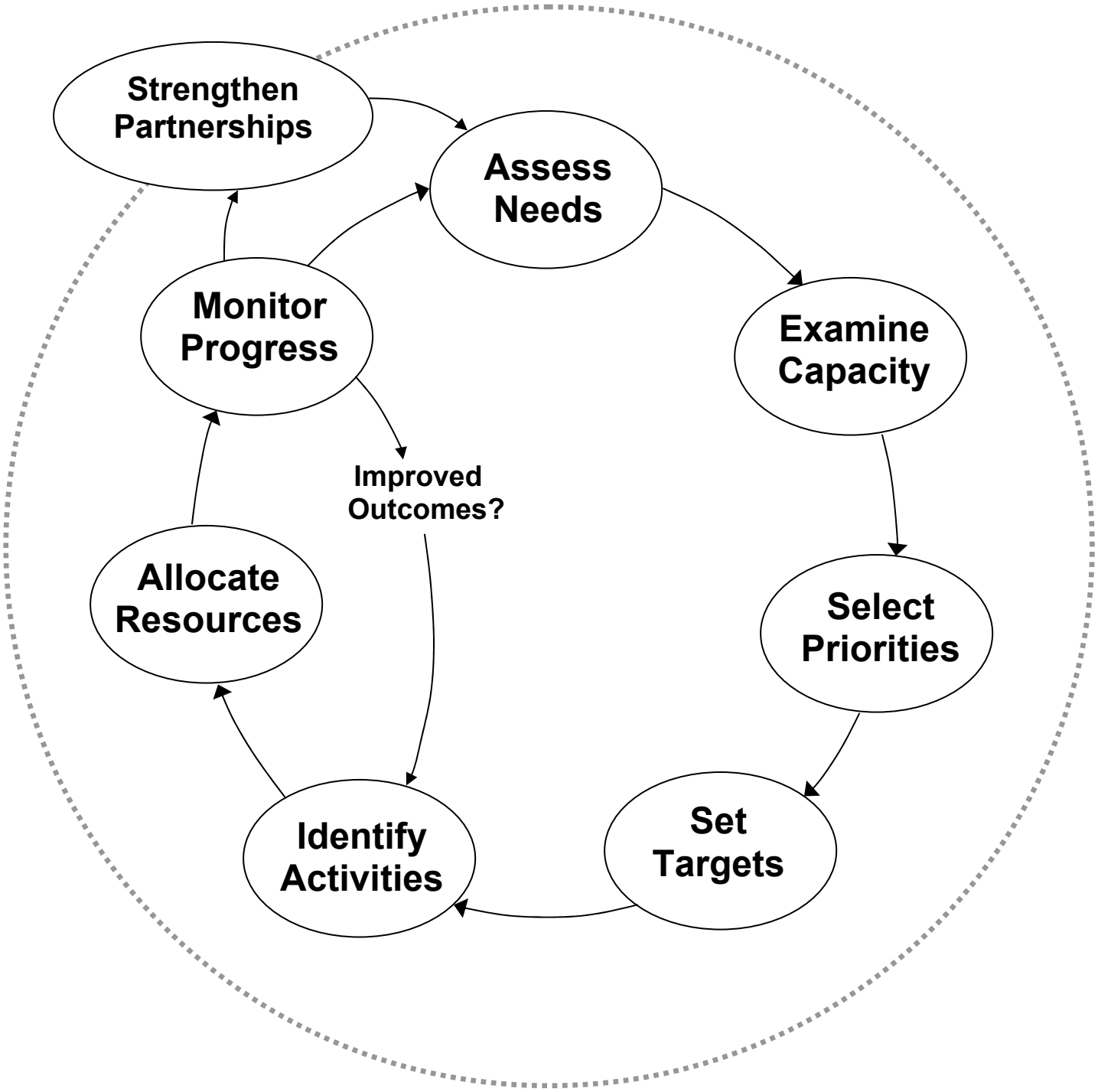
II - NEEDS ASSESSMENT

II.A. Needs Assessment Process

The New Jersey Title V program, the Division of Family Health Services, has prepared the following needs assessment that identifies consistent with health status goals and national health objectives the need for: preventive and primary care services for pregnant women, mothers and infants; preventive and primary care services for children; and services for CSHCN. This section relates the needs assessment process in New Jersey and the planning and monitoring functions to the conceptual needs assessment in Figure 3 Overview of the MCH Needs Assessment, Planning, and Monitoring Process. Though many of the functions occur simultaneously the sequential process is described below. This is a continuous and on-going process throughout the year.

An ultimate goal of the needs assessment is to strengthen partnerships and collaboration efforts within FHS, NJDHSS, the MCH Bureau, and other agencies and organizations involved with MCH. As depicted in Figure 3, the starting point is to assess needs of the MCH population groups using Title V indicators, measures and other quantitative and qualitative data. The outcome of the assess needs stage is the identification of the specific needs of MCH population groups.

The second stage in the process, examining capacity, is an assessment of the ability to provide services at the four levels of the MCH services pyramid: direct health care services, enabling services, population based services, and infrastructure building services. This stage involves describing and assessing the State's current resources, activities, and services as well as the ability to continue to provide quality services to each of the pyramid levels. The outcome of the examining capacity stage is a better understanding of capacity to meet needs.



Overview of the MCH Needs Assessment, Planning, and Monitoring Process

In the select priorities stage, the State selects it's most important MCH needs to receive targeted efforts for improvement. The inputs include: the needs assessment, the examination of capacity, and the political priorities within the State. The outcome of the select priorities stage is a set of priority needs which are described in Section IV.B. State Priorities.

The set targets stage consists of two phases. First, state-negotiated performance measures to monitor progress on state priorities, not already monitored through national performance and outcome measures, are selected. State-negotiated performance measures are summarized on Form 11. Second, state and national performance targets and outcome measure targets are set for the next five years.

The next stage is to identify activities to meet priority needs. Activities addressing individual priorities are outlined and summarized in Figure 4A and in Figure 4B.

In the allocate resources stage the focus is on planned activities to meet priority needs. The inputs include planned activities, previous budgets, political priorities, and partnerships with the outcomes of a budget and improved outcomes.

In the final monitor progress stage, the State looks at the outcomes to see if the resultant products are an improvement. The inputs include the state performance measures, national performance measures, outcome measures, targets, and other quantitative and qualitative information. The outcomes include altered activities and shifted resource allocation. There are several feedback loops between various stages which allow for continuous input and re-evaluation of the outputs.

II. B. 1. Five Year Needs Assessment Process

The completion of a comprehensive needs assessment for the MCH population groups is a continual process that the Division of Family Health Services performs in collaboration with a number of other organizations. The overall needs assessment methodology is similar for each of the three population groups - preventive and primary care services for pregnant women, mothers and infants; preventive and primary care services for children; and services for children with special health care needs.

The annual State budget process includes several steps that are very similar to the stages and functions to the MCH block grant needs assessment. In preparation for the annual State budget hearings where the department's budget priorities are presented to the Governor and legislature, FHS reviews and summarizes programmatic activities, service capacity, budgets, and emerging issues. Activities, budgets and priorities are justified in terms of standard health indicators and program evaluation data. This annual several month process takes place at the program level, the division level, then the department level, and finally is presented to the Governor and in turn the legislature. The annual State budget process overlaps with the MCH needs assessment process beginning in October and ending in April.

Divisional and departmental strategic planning has also contributed to the needs assessment process. The development of strategic plans is an internal process to identify priority needs, establish performance measures, set targets and develop detailed plans. A FHS strategic plan including goals, objectives and strategies was completed in June 2000. Many of the Healthy People 2010 objectives and the MCH Block Grant national and state performance measures are included in both the departmental and divisional plans. Strategic plans that are specific to targeted areas have also been developed and assist the Division in setting priorities. Targeted plans include those developed for teen pregnancy prevention, asthma, childhood lead poisoning prevention, and one developed by the Physical Fitness and Sports Council.

The development of Healthy New Jersey 2010, the New Jersey state equivalent of Healthy People 2010, has been a major departmental planning and needs assessment process that incorporates the MCH population. Establishment of an interdepartmental steering committee in

January 1999 initiated the Healthy New Jersey 2010 development process. Representation included the Departments of Health and Senior Services, Environmental Protection, Human Services, Education, and Law and Public Safety. A divisional FHS subcommittee was formed to develop objectives for MCH areas covered in the chapters on Healthy Mothers and Young Children, Health Behaviors - Adolescents, Diabetes, and Asthma. The document identifies approximately 140 key indicators of the health status of New Jersey's residents, along with ambitious year 2010 targets for improvements. One of the overarching goals for public health improvement is the elimination of health disparities. Public input was received through comments on a disseminated draft document and public hearings held in three sections of the State. An electronic copy of Healthy New Jersey 2010 is available at www.state.nj.us/health/chs/hnj.htm. An important role of Healthy New Jersey 2010 is the objective monitoring and targeting of key health status indicators, very similar to the target setting of the MCH block grant performance measures, outcome measures, and health system capacity indicators.

Advisory groups and task forces provide valuable expert input, public and private constituency representation, and family member involvement into the MCH needs assessment process. Examples of key MCH advisory groups and task forces include: NJ Interagency Task Force on the Prevention of Lead Poisoning, Advisory Council on Adolescent Pregnancy, Medicaid Managed Care Alliance, New Jersey Council on Physical Fitness and Sports, Newborn Screening Annual Review Committee and the Statewide Parent Advocacy Network (SPAN) for CSHCN. Other detailed descriptions of collaborative processes and partnerships with the public and private sector and other state and local levels of government are included in Section III.E. State Agency Coordination.

At the regional level the MCH Consortia conduct planning and needs assessment to promote a coordinated prevention-oriented approach to MCH services. Through regulations, each MCH Consortium must submit to the NJDHSS a regional perinatal and pediatric plan for approval. It was a consensus of the Maternal and Child Health working group to move the submission of the regional perinatal and pediatric plan from three years to five years with updates to the plan every year. The regional plans must address pediatric morbidity and mortality, risk-appropriate

prenatal care, low birth weight, and teen births. The social, cultural, economic and demographic factors influencing the perinatal and pediatric needs of their communities must also be described. These plans serve as a guide for the MCH Consortium and its members in the development, coordination and evaluation of services for pregnant women, infants, children, and adolescents in the communities they serve.

The grant awarding, renewal and monitoring processes continually assess local needs that are specific to geographic areas. FHS funds numerous grantees involved with MCH programs on a regional or local level. The selection process includes a review of local identified need. Renewal and monitoring of grantees is based on measurable outcomes that are designed to address identified needs. Many of the agencies that are awarded health services grants by FHS use the MCH Block Grant performance measures or Healthy People 2010 objectives as their outcome measures. Examples of local grants include case management to assist primary health care providers through PORsCHE, and local planning and perinatal outreach through Healthy Mothers /Healthy Babies Coalitions.

The quantitative surveillance and analysis of MCH data by the MCH Epidemiology Program provide continuous input into the needs assessment process. The MCH Epidemiology Program produces standardized MCH health indicator reports for FHS, for the MCH Consortia, and for other public health related organizations by special request. The MCH Epidemiology Program works with the Vital Statistics Program, the Center for Health Statistics, other departments in NJDHSS, and the MCH Consortia Data/TQI Workgroup to support data needs for regional planning. The MCH Epidemiology Program also conducts applied research projects which currently focus on issues related to breastfeeding, smoking and pregnancy, prenatal care utilization, identification of risk factors for adverse birth outcomes, childhood asthma and longitudinal birth histories.

Public comment on regulations and publications is an ongoing process of needs assessment and input from both public and private constituents. Rules implementing laws sunset every five years, and therefore, programs must readopt rules every five years. Proposed rules are published in the New Jersey Registry (NJR) with a 60-day open comment period. Responses to all public

comment must be published, along with possible changes to the proposal before adoption of the rules (also published in the NJR). Public comment on the development of the MCH Block Grant application is also encouraged through a public hearing on the MCH Block grant held annually in May. A draft of the narrative is posted to the Department's website four weeks prior to the public hearing.

The selection of the state's eight priority needs is a product of FHS's continuous needs assessment. Influenced by the departmental budget process, the MCH Block Grants needs assessment process and the collaborative process with other MCH partners, FHS has selected the eight priorities listed in Section IV.B. State Priorities. Some of these priorities have been longstanding priorities (SP #2 Decreasing Black Infant Mortality, SP #3 Decreasing Teen Pregnancy, SP #7 Improving and Integrating Information Systems, and SP #8 Improving Access to Quality Care for CSHCN). Others are priorities that broadly address several issues (SP #1 Decrease Adolescent Risk Taking, and SP #4 Increase Healthy Births). The remaining two priorities focus attention on more recent public health issues (SP #5 Improving Nutrition and Physical Fitness, SP #6 Decreasing Asthma Hospitalizations).

The current methods and procedures for the comprehensive needs assessment have both strengths and weaknesses. The evolution of the MCH Block Grant to include standardized performance measures, outcome measures, and health systems capacity indicators has added structure and accountability to the needs assessment process. Each year the state is able to build and add detail to prior needs assessment efforts. Utilizing the departmental budget process is also an efficient use of time and effort. One strength that may be unique to New Jersey is the role the MCH Consortia play in contributing valuable information to the Title V comprehensive needs assessment. The multiyear plans that are developed by the MCH consortia serve as regional assessments for the statewide Title V needs assessment.

A general weakness or challenge of the needs assessment process is recording the breath and diversity of activities that could be included under a comprehensive needs assessment. New Jersey's Title V activities intersect with numerous other federal and state programs, making it difficult to identify what most appropriately falls under the Title V needs assessment and what

does not. Many activities that come to the attention of FHS staff are relevant to the MCH populations but may not be specifically administered or "formally" linked with Title V programs. Additionally, not all activities at the state, regional or local level are recognized as having relevance to the Title V needs assessment. There are numerous activities that other public or private organizations are involved with that affect the public health of MCH populations that are carried out without FHS involvement. Limitations in the scope of influence and accountability of FHS, limitations of staff, and limitations of funding must be recognized. However, we believe that the major activities and priorities effecting MCH services are being addressed.

II.B.2 Needs Assessment Partnership Building and Collaboration

An important goal of the needs assessment process is to build and enhance partnerships between MCH programs within FHS and other organizations. This section describes the partnerships between MCH programs and other HRSA programs, other departmental programs, and other state and local organizations.

The MCH programs in FHS have partnered with the HRSA programs in the area of primary health care, addressing health professional shortages and HIV/AIDS. In New Jersey, the geographic distribution of primary care providers including family practitioners, general pediatricians, obstetrician/gynecologists has improved. FHS personnel serve on the New Jersey State Primary Care Loan Redemption Program steering, and selection committees. This provides an opportunity to address shortages of health professionals in areas of the State that impact on the maternal and child health populations. New Jersey has actually lost many (438 site locations) of our federally designated health professional shortage areas due to revised Federal poverty requirements. In addition, the enrollment of New Jersey's Medicaid eligible recipients into managed care and increasing provider capacity may also contribute to the loss of designations. However, all New Jersey counties that are designated as Medically Underserved Areas/Populations have a funded federally or state designated community health center site.

To address the limited enrollment of adolescents in New Jersey FamilyCare, NJDHSS is collaborating with the Department of Human Services and the Region II Field Office of the Health Resources and Services Administration (HRSA) in the NJ Family Care: Adolescent

Enrollment and Utilization of Health Services project. While some outreach and enrollment activities have been targeted toward this population group through schools, these achieved limited success. Under the HRSA/Center for Medicare and Medicaid Services CompCare initiative, consultants from Health Systems Research, Inc. have interviewed State staff and key community informants, conducted focus groups with adolescents and parents, and are developing recommendations for addressing the barriers to adolescent enrollment in health insurance and utilization of appropriate health services.

The New Jersey Department of Health and Senior Services is a member of the New Jersey Oral Health Coalition, an organization established in October 2000, comprised of individuals from private and public agencies located throughout the State. The mission of the Coalition is to foster and promote the equitable access of quality oral health care services throughout the State. This mission is being accomplished through the establishment of private and public partnerships, as well as through linkages amongst both professional/consumer organizations and all levels of government. The HRSA Region II dental consultant was chairman of the Coalition until his retirement in 2002. The Oral Health Coalition sponsored the first Annual Oral Health Summit on September 12, 2001. The 2005 Oral Health Summit with the New Jersey Oral Health Coalition was held on April 27, 2005 with representatives from academia, private dental practices, insurance industry and health educators attending. Sessions focused upon access to care, oral health education in the school setting and the correlation between oral health and general health.

To reduce the perinatal transmission of HIV, each of New Jersey's seven Ryan White Title IV Family Centered HIV Care Network Centers has a dedicated perinatal care coordinator who is responsible for targeting outreach, counseling, testing and long-term follow-up of high risk adolescents and women of child bearing age. Pregnant women identified as HIV positive are referred to specialty clinics within the network. AZT treatment is provided during pregnancy, delivery and to newborns according to the CDC protocol. Co-located mother-child or family clinics have been established in each site to facilitate long term maintenance of mother and child in care. In conjunction with the Division of HIV/AIDS Services, the Network established a Perinatal HIV Advisory Committee in 2000 to develop a statewide policy for rapid testing and short course therapy to reduce the risk of perinatal HIV transmission in women who present in

labor with an unknown HIV serostatus. Committee representation included Family Health Services MCCH and SCHEIS staff, MCH consortia, OB and pediatric providers, Medicaid, and Ryan White Title IV Executive staff. In 2001 the *Standard of Care for Women Who Present in Labor with Unknown HIV Serostatus* was developed. The intent of the Standard of Care is to provide HIV counseling and voluntary rapid or expedited testing of mothers in labor or delivery, or newborns in nursery units, if there is no documentation of prior HIV testing. Maternal and/or newborn antiviral therapy will be offered if the test is reactive. With supplemental funding received in 2002 from the CDC, NJDHSS engaged the National Pediatric and Family HIV Resource Center to develop and implement a statewide Train-the-Trainer program. In FY 2003, the Division of AIDS Prevention and Control a statewide survey to determine the effectiveness of the training sessions on further reducing perinatal transmission.

Efforts to build and enhance partnerships between MCH with other programs within the NJDHSS occur in many areas including asthma, injury, immunizations, lead poisoning, cancer, obesity and physical activity, sexually transmitted infections, women's health and perinatal HIV. Examples of important collaborations are described in and will be updated annually in Section III. E. State Agency Coordination. Collaborations have developed through several process including shared departmental goals (immunizations), shared grants (ASTDR asthma grant), joint educational events (women's health conference), and interdepartmental planning (asthma strategic plan).

Efforts to build and enhance partnerships between MCH programs and other governmental agencies are also described and will be updated annually in Section III.E. State Agency Coordination. Methods to build partnerships include shared goals and planning (Strategic Plan of School Age Health), shared funding (FAS, Child Care America Grant), and joint educational events (Child Care Conference). Other examples include the Child Fatality and Near Fatality Review Board, FAS Task Force, Interagency Task Force on Childhood Lead Poisoning and the Work First Teen Pregnancy Prevention Interdepartmental Work Group.

Efforts to build and enhance partnerships between MCH and other state and local public and private organizations have resulted in a coordinated and regionalized system of MCH services in

New Jersey. Important partnerships occur at all levels including the state, regional, county, municipal, local organization, and the individual. Methods used to build and enhance partnerships include local grants (PORSHE and Black Infant Mortality Reduction), data sharing (MCH Consortia), education and training (BIMR Resource Center), infrastructure building (Statewide Parent Advocacy Network). Other examples are detailed in and will be updated annually in Section III.E. State Agency Coordination.

II.B.3. Assessment of Needs of the Maternal and Child Health Population Groups

Overall the majority of health measures concerning Title V as measured by national performance measures, state performance measures, outcome measures and the new health status indicators are stable or improving. The following section addresses the major health issue areas within the three MCH population groups, highlighting relevant gaps in access to service, disparities in health indicators, and cultural competency of services. Statewide trend charts for key national performance measures, outcome measures, and health system capacity indicators mentioned in this section are presented in the Appendix (Charts 1-11).

A. Pregnant Women, Mothers, and Infants

For pregnant women, measures of prenatal care utilization (PM #18, HSCI #4, HSCI #5) have improved slightly statewide for all major race/ethnic groups. First trimester initiation of prenatal care has been level while there have been encouraging recent increases in adequacy of prenatal care as measured by the Kotelchuck Index and a decrease in no prenatal care (Charts 2&3). Although the relationship between prenatal care and pregnancy outcomes is very complex, timely prenatal care is necessary for early risk assessment to prevent or treat medical conditions, and for offering health behavior advice such as smoking cessation, breastfeeding, and nutrition counseling.

Infant Mortality Rates (IMR) have declined significantly in New Jersey since 1990. Chart 8 illustrates the decline in the neonatal mortality rate and the postneonatal mortality rate. The greatest decline in infant mortality appears to be in early neonatal mortality (Chart 8). Race and ethnic differences in IMR remain a major concern (Chart 7). Although all race/ethnic groups

have experienced declines in IMR, the relative difference in rates between black non-Hispanic and white non-Hispanic newborns, expressed as the ratio of black to white IMRs, remains at 3.8 for 2002 data. The Black Infant Mortality Reduction initiative targets this disparity in infant mortality rates through increasing public awareness, professional provider education, in addition to funding seven health service grants. The HMHB Coalitions target the eleven cities with the highest infant mortality rates, low birth weight rates, and inadequate prenatal care rates. Three federally funded Healthy Start projects exist in Camden, Trenton and East Orange.

Black infant mortality Reduction projects seek to improve birth outcomes for pregnant black women. Indicators of infant mortality, fetal mortality, low birth weight and prematurity (PM#15, OM #1,2,4,5,7, SPM#1, HSCI#5) have all remained higher for infants of black mother (See charts 7,8,5,6). The goals of the projects are to reduce black infant mortality by using case management, outreach and client recruitment and risk reduction. Social support mechanisms such as mentoring, stress management, risk reduction counseling, health education and other methods are used to decrease psychosocial stress due to internal as well as external forces. These projects provide community-based, culturally sensitive, comprehensive perinatal services, outreach and client recruitment, health promotion, risks and stress reduction and education. These agencies also provide education to health care providers and the general community about the issue of black infant mortality and its related issues. A broad network of collaborative efforts with a mixture of community-based agencies, institutions, religious, education and grassroots groups will compliment other Department initiatives. These agencies target diverse subgroups within the black community, including substance abusers, adolescents, homeless, poverty-stricken and isolated perinatal families.

Disparities in perinatal outcomes also exist on the geographic level where a combination of sociodemographic and situational factors combine to define high need areas. The MCH Epidemiology Program has recently reviewed and improved its methodology to identify high need areas based on perinatal measures at the municipality level. Review of the methodology and use of more recent data confirmed priority status of the eleven Healthy Mother / Healthy Baby municipalities originally identified in the 1980s. Six new municipalities were identified as

high need, four of which are included due to a lower threshold of births in the new ranking methodology.

Conforming the targeting of initiatives to high needs municipalities, the Department was awarded in 2002 an Eliminating Disparities in Perinatal Health (Healthy Start) grant to improve pregnancy outcomes and reduce infant mortality in East Orange, Essex County. This Healthy Start Initiative complements other Reproductive and Perinatal Health Services projects focusing on East Orange, Essex County, an urban municipality containing a large concentration of poverty and disadvantaged minorities in the County and State. A comprehensive case management model with outreach, client recruitment, and health education was implemented. The approach will be to ensure culturally competent care to improve the health outcomes of the diverse African-American population. This model increases the percent of pregnant women receiving earlier and regular prenatal care. The initiative coordinates parenting education, child abuse/neglect prevention, family planning, depression/mental health, interconceptual care, increase referral for maternal primary care and pediatric primary care, improve immunizations rates, and promote smoking cessation, substance abuse risk reduction and stress management. Community members and health care providers receive community education about black infant mortality and related issues. Health care providers receive cultural awareness/competency training.

Low birth weight is one of the most important predictors of infant mortality. The higher risk for infant mortality among blacks compared to whites can be attributed to higher risk of death among normal birthweight infants. Birth weight-specific infant mortality rates illustrate that the higher black infant mortality rate (IMR) is also due to a higher incidence of very low birth weight (VLBW).

Measures of low birth weight (LBW) and very low birth weight (VLBW) have increased since 1990. However, LBW rates and VLBW rates for singleton births as illustrated in Chart 4 are fairly stable or decreasing. The rise in multiple births, driven by an increase in assisted reproduction and older mothers, has markedly influenced overall rates of LBW, VLBW and prematurity. Multiple births greater than twins have increased over 500% since 1989. New

methods of reporting LBW rates should be standardized to account for the rise in multiple births and multiple pregnancies.

The disparity in LBW rates by race and ethnicity are particularly concerning due to the role of birthweight in infant mortality and the long-term effects of LBW including neurologic disorders, learning disabilities, and delayed development (Chart 5, 6). Given the multi-factorial nature of LBW, FHS has focused on improving services that are likely to influence LBW such as preconceptional care, early prenatal care and the regionalization of perinatal specialty services.

In order to reach the greatest number of women possible, Reproductive and Perinatal Health Services moved from the policy of providing health services grants to individual agencies that provide direct services to a more integrated statewide approach through the Maternal and Child Health Consortia (MCHC). The six MCHC are charged with providing prevention activities, consumer and professional education, total quality management, data analysis, infant and pediatric follow-up, coordination of perinatal/pediatric transport systems, and the development of comprehensive perinatal/pediatric plans for their respective regions. The Consortia were the most appropriate vehicles to influence and assist all perinatal and family planning providers (public and private) in their regions to upgrade their ability to address substance abuse issues within their practice. Since 2001, each of the six Consortia is required via a grant award to maintain, at a minimum, one full time equivalent Regional Risk Reduction Specialist/Coordinator who is responsible for the following activities in the region including but not limited to:

Ensure that all prenatal and family planning service providers within the regions disseminate information and literature that address the effects of alcohol and other substances on pregnancy outcome

Assist all prenatal and family planning service providers in the region, to address perinatal addiction and to offer access to or incorporate perinatal addiction risk reduction services within their practice.

Increase the identification of substance abusing pregnant women and infants with drug related disabilities and provide or refer them to appropriate services.

Introduce a standard screening tool and collect data about the risk behaviors of pregnant women.

Despite the overwhelming evidence supporting the numerous benefits of breastfeeding, exclusive breastfeeding rates in New Jersey have been declining slightly. Numerous collaborative initiatives are underway to promote breastfeeding and improve breastfeeding duration. Breastfeeding promotion activities have been funded statewide by the WIC program to MCH Consortia and local WIC agencies. Lactation consultants and peer counselors provide direct education and support services. Literature, education and breastfeeding aides including pumps are made available. Professional outreach and education are provided. Using breastfeeding at hospital discharge data from the Electronic Birth Certificate, increasing exclusive breastfeeding initiation rates has been identified as a major objective. Exclusive breastfeeding rates have been declining slightly the past several years, while any breastfeeding rates have increased slightly (see chart 9). Breastfeeding rates at discharge by hospital varied inversely with the minority composition of mothers. Further examination of this disparity will require information of locally available breastfeeding promotional activities and the cultural competency of those services.

Teen pregnancy prevention continues to be a priority for interagency action in New Jersey. Overall there has been a steady reduction in teen births for all race/ethnic groups (Chart 4). While birth to teens in New Jersey have consistently been below the national average for several decades, this obscures the fact that every year there are almost 7,000 births to teens (< 20) statewide. By virtue of their age alone, the vase majority of teens are ill equipped to deal with the emotional and economic stresses of being a parent. A description of initiatives to reduce teen pregnancy is presented in Section IV.C. National Performance Measures. Family Health Services had been concerned about an upward trend in Hispanic teen births, which now appears to be reversing.

The frequently overlooked areas of preconceptual health care and women's health are being addressed through outreach and education programs sponsored by the MCHC and HM/HB Coalitions. Preconceptual health is being integrated with ongoing MCH programs, conferences are presented by the MCHC and HM/HB as well as joint projects with other agencies. Included

in this Preconceptual Health Promotion Program is the Folic Acid Initiative which focuses on preventing neural tube defects.

More qualitative methods of assessing perinatal health occur through the New Jersey Fetal Infant Mortality Review and New Jersey Maternal Mortality Review process. Information collected from these review processes, including data and issues identified by the Case Review Team, will be analyzed and used in the need assessment process at the State level for program planning and policy development. Region-specific findings from the review process will be provided to the MCH Consortia to be utilized in their continuous quality improvement activities and for utilization by their member hospitals for quality assurance activities.

The Maternal and Child Health Consortia are required through regulation to complete and submit a Regional Perinatal and Pediatric Plan every three years. This plan includes the following components: a needs assessment that describes the current status of maternal and child health services in the region, an assessment of gaps in services, and a list of objectives and a plan to address the identified gaps. The Division of Family Health Services in consultation with the MCHC Working Group is investigating the possibility of revising the current regulations to require a five-year plan to coincide with the MCH Block schedule.

B. Child Health

Improving access to preventive and primary care health services for children is a departmental and divisional priority. To provide comprehensive and affordable health insurance to eligible uninsured children, New Jersey and the Federal government have joined as partners in NJ FamilyCare (formerly New Jersey KidCare). NJ FamilyCare, administered by the New Jersey Department of Human Services, started in 1998. In the course of developing NJ FamilyCare, the State learned that many poor children who are eligible for free health insurance under the State's Medicaid program are not enrolled. The aggressive marketing and outreach programs designed to enroll children in NJ FamilyCare are also being used to increase the number of children enrolled in Medicaid. If all children who are eligible for NJ FamilyCare or Medicaid enroll in these programs, then the percentage of children who are uninsured should drop to four percent.

Of the approximately four percent of uninsured children who do not qualify for NJ FamilyCare or Medicaid, many experience temporary gaps in insurance coverage, usually as a result of changes in parental employment. If employer-sponsored health insurance continues to decline, however, NJ FamilyCare will not be able to reduce the overall number of uninsured children in the State. For this reason, New Jersey wants to support, not compete with, employer-sponsored health insurance.

The limited enrollment of adolescents in New Jersey FamilyCare and subsequent low utilization of services is of concern to State officials. While some outreach and enrollment activities have been targeted toward this population group through schools, these achieved limited success. To address this concern, DHSS is collaborating with the Department of Human Services and the Region II Field Office of the Health Resources and Services Administration (HRSA) in the NJ Family Care: Adolescent Enrollment and Utilization of Health Services project. Under the HRSA/Center for Medicare and Medicaid Services CompCare initiative, consultants from Health Systems Research, Inc. have interviewed State staff and key community informants, conducted focus groups with adolescents and parents, and are developing recommendations for addressing the barriers to adolescent enrollment in health insurance and utilization of appropriate health services.

In addition to exploring ways to make health insurance more affordable and accessible, New Jersey continues to support a health care safety net. All New Jersey hospitals are required to provide needed care to patients, regardless of their ability to pay for this care. In return for hospitals fulfilling this obligation, the State continues its long-standing practice of contributing to the cost of this charity care, providing $583.4 million in SFY2005 to hospitals for uncompensated care relief.

In New Jersey, the geographic distribution of primary care providers including family practitioners, general pediatricians, obstetrician/gynecologists has improved somewhat. Recent primary care access reports indicate that New Jersey has lost many of our federally designated health professional shortage areas due to the Federal requirement that 30% of the population in a requested area be at or below 200% of the Federal Poverty Level. Many of the State's

designations were approved prior to 1995 when the level of poverty required was 20%. In addition, the enrollment of New Jersey's Medicaid eligible recipients into managed care and increasing provider capacity will also contribute to the loss of designations. The Advisory Committee on Primary Care Areas created by FHS in December 1999, completed its final recommendations on the designation of statewide Rational Service Areas which were approved by the Department in 2001. These service areas are used in preparation of applications submitted to the Bureau of Health Profession Shortage Designation Branch requesting health professional shortage area designations. Representation on the committee included professional medical societies, Maternal and Child Health Consortia, HRSA Field Office Region II, and staff from the Bureau of Primary Health Care, Division of Shortage Designation.

The State supports a Primary Care Health Professional Loan Redemption Program and has also instituted a State 30 J-1 Visa Waiver/State 30 program to meet the critical need for certain primary care providers in our most underserved areas. Dental care continues to be an area of concern. Although included as part of the managed care package, many of the State's underserved still have difficulty accessing dental services. FQHCs have continued to increase their capacity for providing dental services, but several still have significant waiting lists.

Financial access to health care is a necessary but not sufficient condition to ensuring true access to care. There are many barriers to access besides cost. Physicians or clinics may not be located in places where people can reach them easily, particularly people who lack private transportation. Office or clinic hours may not be convenient for people who are working or going to school. A lack of culturally competent care is of particular importance to eliminating health disparities. New Jersey is a highly diverse state and growing more so every year. It is important that all health care providers understand and value the cultures of their patients in order to better serve their health needs.

Significant progress has been made toward childhood lead poisoning prevention which is an important health issue for specific populations in the state. During State FY 2003, more than 183,000 blood lead tests were reported on 172,932 children. Of these children, 90,112 were between six months and 29 months of age, the ages at which state rules require all children to be

screened for lead poisoning. This is 40% of all children in that age group. Among all children in New Jersey who were two years old during SFY 2003, it is estimated that 68.6% have had at least one blood lead test in their lifetime. Children in New Jersey have a higher than average exposure to lead in their environment and a higher percentage of elevated blood lead than the national average. Of the children tested, 3.0% had results $\geq$ 10 ug/dl and <1% had results $\geq$ 20 ug/dl. Children with elevated blood lead levels are at increased risk for behavioral, physiological and learning problems.

The NJ DHSS maintains a data system to receive elevated blood lead reports from laboratories and to notify local health departments. Local health departments are required by State law to investigate every case of lead poisoning and to order the remediation of any environmental lead hazards found. The information compiled by the NJ DHSS enables the department to monitor compliance with the State law requiring lead screening of all children and to better target prevention activities to the areas of greatest need. While there were children reported with lead poisoning from every county, the majority of affected children are living in the State's major urban centers. Over one-third of affected children resided in Newark.

In the highest risk city, Newark, the Child and Adolescent Health Program has partnered with the Newark City Department of Health and Human Services (DHHS) to establish the Newark Partnership for Lead Safe Children. The partnership has enlisted the support and participation of over 50 agencies/organizations in Newark. The partnership has been designed to empower the city and participating organizations to "take charge" of the lead problem in Newark. DHSS is working in collaboration with the Department of Human Services, which is responsible for Medicaid and SCHIP in New Jersey, in sponsoring pilot projects to test the effectiveness of innovative methods to promote lead screening. These projects started in August 2002 and are in the cities of Camden and Irvington.

Asthma has been identified as the most common chronic disease in children. In New Jersey in 2003, there were 4,772 hospitalizations among children <18 years old where asthma was the primary diagnosis. In the Special Child Health Services Registry, asthma is a condition for which voluntary registration is accepted, but less than 3,000 children are currently registered. A

federal CDC grant, awarded in August 2000, is supporting the development of an asthma surveillance system for New Jersey. These funds enabled the hiring of a full-time asthma epidemiologist, in the MCH Epidemiology Program. Surveillance projects have included the completion of an annual Asthma Surveillance Report, an investigation of the impact of readmissions on pediatric asthma hospital admission rates, and an investigation of the association of aeroallergens and pediatric asthma hospitalizations. Strategic plans have been produced by the Interdepartmental Working Group on Asthma and the Pediatric Asthma Coalition of New Jersey.

New Jersey ranks 48th among the States in the percentage of the population receiving optimally fluoridated drinking water. In response to this, an emphasis has been placed on individual actions by parents and children to prevent tooth decay. National statistics from the National Institutes of Health (NIH) indicate that nearly 20 percent of children between the ages of 2 and 4 have had tooth decay and almost 80 percent of young people have had a cavity by age 17. Water fluoridation, dental sealants and regular professional dental care are among safe and effective measures currently available for preventing and treating dental caries. Current statewide activities targeted to prevent tooth decay include the children's voluntary school-based fluoride mouth rinse program, "Save Our Smiles" targeted to schools in underserved communities that do not have optimally fluoridated water. The Fluoride Mouth Rinse Program is the most active intervention to reduce the number of diseased, missing and filled surfaces on the teeth of school age children. Additional efforts include classroom oral health activities such as the Cavity Free Kids Program that reached over 2500 children at over 50 schools, education efforts directed towards the use of dental sealants, preventive oral health, and nutrition education in a variety of settings. The "Miles of Smiles" oral health education newsletter is another venue that promotes preventive oral health education. This newsletter is mailed annually to over 3000 schools and local health departments.

During the 2004-2005 school year a random sample of schools participated in a dental sealant survey which estimated that a dental sealant was present on a back tooth of 42% of the third grade students. Sealant usage varied according to per capita income and region of the state.

Efforts to identify the needs of adolescents are ongoing. There is, however, clear evidence that to improve the health status of the adolescent population and to decrease mortality and morbidity, efforts must increase to reduce adolescent risk-taking behavior. The strategies to be employed are not limited to enabling services but must include approaches that touch all levels of the MCH services pyramid. For the pregnant or parenting teen, supportive home visitation services seek to improve a teen's parenting skills, encourage healthy lifestyle choices, and ensure that the infant and mother get the health, educational, and social services needed.

Injuries are the leading cause of death among children aged 1-24. Leading causes of injury deaths in children are motor vehicle crashes, fire-related injuries, homicide and drowning. Motor vehicle crashes remain the leading cause of mortality among persons 15-24 years in New Jersey and the nation. Homicide is the leading cause of death among black males 15-24 years of age with a large proportion attributed to firearms. Suicides are lower in New Jersey than the country as a whole. However, it's the third leading cause of death among the youth 10-24 years. Two-thirds occurred among males with highest rates occurring among males 20-24 years. Developing effective interventions to reduce cause specific mortality for youth is needed, as well as addressing underlying root causes of mortality such as risk-taking, substance abuse and violence.

The use of tobacco products by youth is a public health issue that is receiving increasing attention. In 1995, almost 40% of high school students in New Jersey reported using cigarettes. The New Jersey Comprehensive Tobacco Control Program conducts the bi-annual Youth Tobacco Surveillance Survey to collect statewide data on knowledge, attitudes and behaviors of youth regarding tobacco. Current use of any tobacco (defined as any tobacco use on one or more days in the 30 days preceding the survey) for among high school students significantly declined from 38.9% in 1999 to 26.8% in 2004. Current use of cigarettes (defined as smoking a cigarette on one or more days in the 30 days preceding the survey) for among high school students significantly declined from 27.6% in 1999 to 17.3% in 2004. A new anti-tobacco campaign focusing on high school-age and middle school-age youth titled, "Reaching Everyone By Exposing Lies (REBEL)" is underway to decrease youth initiation of tobacco.

Staff from Maternal, Child and Community Health work cooperatively with the Comprehensive Tobacco Control Program on initiatives to reduce adolescent tobacco use. Staff has actively participated on the CDC Tobacco Control Advisory Panel. This Advisory Panel provides structure and guidance to regional coalitions throughout the State who implement tobacco prevention programs at the local level. The Preventive Oral Health Education Program targets tobacco prevention in its oral health education for middle school students. The curriculum "Mr. Gross Mouth" discusses the oral health problems of oral cancer and gum disease associated with smoking and chewing tobacco. As part of the Family Planning Program's Adolescent Enhanced Service Program, assessment education and follow-up regarding the risk of smoking are routinely provided to participating teens.

By implementing more health promotion risk reduction and youth asset development programs at the local level for the adolescent population, chances will increase for reducing the adverse consequences often associated with risk taking behavior: adolescent pregnancies, STIs, violence and intentional and unintentional injuries, poor nutrition, physical inactivity and substance use. The Child and Adolescent Health Program will continue to strengthen coordination and collaboration with school-based youth service programs, and improve intra/interagency communication so that limited resources can be effectively utilized to promote comprehensive services. Community Partnerships for Healthy Adolescents continues to support the development of community-based, adolescent-focused partnerships that coordinate and implement activities and initiatives to address the adolescent issues specific to a community, as identified through a needs assessment process.

Results from the 1999-2002 according to the National Health and Nutrition Examination Survey (NHANES), using measured heights and weights indicate that an estimated 16% of youth age 5-19 are overweight. This represents a 45% increase from the over weight estimates of 11% obtained from 1988-94 NHANES. New Jersey is not exempt from this growing epidemic. The Youth Risk Behavior Surveillance (YRBS) survey results of self-reported height and weight data for New Jersey high school students from 2003 show 9% in ten students were overweight, as defined by being in the 95th or greater percentile for BMI by age and sex. However, another

12% of high school students were found to be "at risk" for overweight, as defined by a BMI between the 85th and the 95th percentile.

In New Jersey, results from the self-reported 2001 Behavioral Risk Factor Surveillance System (BRFSS) indicate that of adults 18 years and older, 38.1% were overweight and 19.6% were obese, according to the BMI calculated from reported height and weight. This means that almost three of five (57%) New Jersey adults were overweight or obese. This translates to an estimated 3½ million overweight or obese New Jersey adults. Since individuals tend to over report their height and under report their weight the actual percentages may be even higher.

The causes of childhood obesity are multifactoral and include: Children's increasing consumption of "junk" food and soda, lack of regular exercise. The Departments of Agriculture, Education and Health and Senior Services are committed to working together to address these critical health issues and ensure New Jersey's children have every opportunity to live long, productive healthy lives. At a Healthy Schools Summit, sponsored by Action for Healthy Kids-New Jersey, the Governor's initiative Healthy Choices, Healthy Kids was announced. The initiative included the following: The Department of Agriculture revising state code to require school districts to adopt a nutrition policy that meets or exceeds the USDA's Dietary Guidelines for Americans. To date, public comment on proposed regulatory policy that addresses the nutritional standards of foods sold in New Jersey public schools ended January 14, 2005. Comments are being analyzed and compiled before going to the Governors office and then to the State Board of Agriculture for adoption. The Department also is working to better educate school food service directors and to introducing Jersey-fresh, produce into the schools, which benefits both farmers and kids alike. The Department of Education (DOE) implemented new core curriculum standards that update and strengthen nutrition and physical education standards in schools. For the first time, these standards create stand-alone sections dedicated to nutrition and linking fitness and healthy eating to learning and academic performance/achievement. Nine pedometer projects, targeting approximately 1,250 youth, 10-15 years old will be completed by June 2005. Children and teachers are being outfitted with pedometers and are tracking their progress using activity logs.

In collaboration with the Department of Education (DOE), DHSS collected retrospective height and weight data of nearly 2,400, 6th grade student health records from 40 randomly selected schools of varying socioeconomic strata. The NJ Child Weight Status Report, 2003-2004 is posted on the DHSS website and presentations are being given throughout the State to make the results of this report known. DHSS and DOE are collaborating to determine the next steps for data collection.

The DHSS hopes to expand the "Intergenerational School Breakfast Program". In this program senior volunteers serve as role models and mentors to young children during the school breakfast program. The volunteers read story books to children and teach them about the importance of eating breakfast and good nutrition. The program is active in 19 schools, in 4 counties and 50 active volunteers for the 2003-4 school year. Volunteer recruitment is difficult for this program due to its early schedule (7:30 am), the short length of time for the breakfast period, transportation, parking and reliability of the seniors who volunteer.

New Jersey Action for Healthy Kids (AFHK) was formed as an outgrowth of a National Healthy Kids Summit held in Washington in October 2002. AFHK is comprised of state government representatives, as well as members from the American Dairy Association and Dairy Council, American Cancer Society, N.J. Dietetic Association, N.J. School Food Service Association, the Mid-Atlantic Dairy Association and USDA Food and Nutrition Service Mid-Atlantic Region.

C. Children with Special Health Care Needs

Numerous data sources exist within CSHCN to provide information on needs assessment. A first step in conducting or assessing needs is establishing the extent of need and defining the target population and subpopulations of interest. The Special Child Health Services Registry is a confidential, unduplicated database comprised of two components: Birth Defects and Special Needs. Children with birth defects are required by statute and rule to be reported to the department, and as such, can be considered to be a census of affected children. While there is no mandate to register children in the Special Needs component, the department receives about 3,000 registrations annually for children who have other conditions that may require service

intervention. This portion represents the minimum number of affected children with such conditions.

Activity reports are submitted quarterly by case management units as well as the Specialized Pediatric network agencies and grantees. These reports are used to determine health services indicators and utilization measures. Within Newborn Biochemical Screening, the program keeps detailed records on the number of children followed for each disorder, and the number of confirmed diagnoses.

Each year, over 7,500 children are newly reported to the Special Child Health Services (SCHS) Registry. Of these, about 57% are registered with one or more birth defects while the remaining children have other at-risk or special needs conditions. Reports to the Registry include all newborns diagnosed with metabolic disorders as well as infants and children diagnosed with hearing loss. Between 1995-2003, the rate of birth defects in New Jersey was 40.8 per 1000 live births, consistent with national data. About 61% of the children with birth defects and 47% of children with special needs are reported before their third month of life. As compared to birth data, more males than females are registered with both birth defects and special needs conditions.

Racial data contained in the SCHS Registry had historically included a high percentage of "unknowns," affecting the accuracy of data analysis. Since 1998, staff from the Birth Defects Monitoring Program has been working to link children reported to the SCHS Registry to birth certificate files. The linking has been completed for birth years 1990-2003. This matched dataset now provides more accurate information on the racial characteristics of the children. The racial composition of children born 1995-2003 with one or more birth defects is 55.92% white non- Hispanic, 19.27% black non- Hispanic, 6.25% other non- Hispanic, 18.03% Hispanic and 0.54% unknown, compared to the New Jersey birth distribution of 55.71% white non- Hispanic, 16.17% black non- Hispanic, 14.58% other non- Hispanic, 18.76% Hispanic and 1.80% unknown.

Data from death certificates indicate that congenital anomalies are the leading cause of infant mortality. In 2002, 109 of the 651 infant deaths were due to congenital anomalies. Of the 109

infant deaths due to congenital anomalies, 76 were white infants, and 25 were black infants, and the remaining were of other or unknown race. Additionally, in 2002, congenital anomalies were the second leading cause of deaths among infants and children age 1-4 and the third leading cause of mortality among children age 5-14.

Children with congenital defects also die from other causes. Data from the SCHS Registry indicate that of the 42,152 children born between 1995-2003 and registered with one or more birth defects, 3.7% expired by age one. Birthweight has a profound effect on the mortality of children with birth defects. In a preliminary analysis of birth defect specific mortality, there does appear that some racial differences are present.

During 1995-2003, most children with congenital defects were registered with defects of the heart, great veins and conduction (n=17,129), followed by external/internal genital anomalies (n=5,494), musculoskeletal system defects (n=4,592), and digestive system disorders (n=3,545). Each year in New Jersey, more than 100 children are born with Down syndrome, one of five major heart defects (common truncus, transposition of the great vessels, tetraology of fallot, hypoplastic left heart, and total anomalous pulmonary venous return), or oral clefts.

The SCHS Registry serves as the primary entry into the local, community-based case management system. For children who are still alive at time of registration, a copy of the registration form is forwarded to the case management unit in the county of residence of the child. This includes all children with both metabolic disorders, hearing impairment, other birth defects, and special needs. Compared to other states, this direct link from the surveillance system to the service delivery system is unique. It is both highly effective and cost efficient, and serves as a means of quickly identifying children with special health care needs who may require service intervention. Since nearly 61% of all children are reported to the Registry by three months of age, families receive timely support and information for their children.

The timely linkage of the surveillance and service systems is particularly useful for the Early Intervention System (EIS). Currently, the EIS identifies specific conditions that constitute "presumptive eligibility." These conditions include: Down syndrome, fetal alcohol syndrome,

hearing impairment, vision impairment, autism/PDD, spina bifida, cerebral palsy, trisomies (e.g. 13,18), fragile X syndrome and hydrocephalus. Children presenting with one or more of these conditions are eligible, by virtue of their diagnosis, to receive early intervention services. A recent data analysis was performed to determine the timeliness of identification of children with these disorders. Using data from the Registry, the age at registration was calculated for these specific disorders for children reported to Registry 1995-2003. The results of the analysis show that for all of the conditions, 55% of the children were registered before three months of age, and 81% before age one. For some of the conditions readily identifiable at birth, such as Down syndrome, Trisomy 13, Trisomy 18, other chromosomal disorders, and spina bifida, nearly 71% of children were registered by three months and over 90% before age one. The data support the usefulness of linking surveillance to service delivery.

Improvements in the reporting and tracking of newborn screening programs are evident in the Newborn Biochemical Screening Program and the Early Hearing Detection and Intervention Program. Record linkage between the 1998 Electronic Birth Certificates and the Newborn Biochemical Screening files clearly demonstrated that more than 99.7% of infants born in New Jersey are screened for biochemical defects. Newborn hearing screening rates demonstrated a rapid increase to 98.8% of 2004 births. New Jersey birthing facilities must establish guidelines for follow-up for newborns identified with or at risk for developing hearing loss. Follow-up services must include but are not limited to: 1) confirmatory pediatric audiological assessment, 2) diagnosis of newborns with abnormal or inconclusive test results, 3) submissions of Newborn Hearing Follow-up Report, 4) counseling and educational services for parents, guardians or custodians, 5) explanation of potential effects of hearing loss on development of speech, language, and/or cognitive skills, 6) potential benefits of early identification and intervention.

The Newborn Biochemical Screening and Genetic Services Program is responsible for the follow-up of all newborns with abnormal screening results. There were approximately 3,500 newborns with abnormal results in 2004. Of these, at least 271 were confirmed as having the classical or variant form of a disorder. Additionally, approximately 2,900 babies are identified with sickle cell trait annually. While these results on sickle cell trait indicate a carrier state, with

no treatment required, the Program provides information and offers resources to the families of the affected newborns.

Since the SCHS Registry is a crucial database serving epidemiological, research, linkage to service delivery, and other public health functions, it is critical that the database be complete and accurate. To meet this requirement, a comprehensive quality assurance program has been implemented. Each year, a quality control audit is completed at each maternity and pediatric facility. During these audits, the medical records for a three-month period of births are reviewed and compared to the information in the Registry. This review provides information on the number of children not registered and compares the accuracy of the information provided on the registration form. Upon the conclusion of the audit, a summation meeting is held between Registry staff and representatives of the facility, followed by a written report. Data from these audits indicate that 85-90% of children with birth defects are appropriately reported.

In addition to the audits, other steps have been taken to improve the Registry. As described earlier, linking the Registry to birth certificates expands the information available on each child. Death certificates are reviewed, to ensure complete mortality data, as well as for case finding. The newborn hearing and newborn biochemical screening programs provide reports to the Registry, and are thus linked through the Registry. The database is continuously "cleaned" for duplicates, valid ranges, and logical consistency.

Advisory groups play an important role in providing professional expertise in the area of newborn biochemical screening. Under the current statute and rules, all newborns are now screened for fourteen biochemical disorders: phenylketonuria, galactosemia, congenital hypothyroidism, the hemoglobinopathies, including sickle cell disease, cystic fibrosis, maple syrup urine disease, biotinidase deficiency, congenital adrenal hyperplasia, medium chain acyl-CoA dehydrogenase deficiency, short chain acyl-CoA dehydrogenase deficiency, long chain acyl-CoA dehygrogenase deficiency, very long chain acyl-CoA dehydrogenase deficiency, citrullinemia, and argininosuccinic acidemia. For each of these disorders, biannual meetings are held with the respective consultant groups. These groups are comprised of a wide range of medical specialists and other health care providers involved in the diagnosis and management of

the disorders. The purpose of the consultant meeting is to ensure that testing and follow-up procedures used by the State are reflective of best medical and laboratory practices. Additionally, the medical consultants represent the concerns of families with affected newborns, including such diverse issues as insurance reimbursement, obtaining referrals for appropriate pediatric consultants, and identification of other unmet needs.

Ongoing efforts are made by SCHEIS to support agencies providing direct specialty and sub-specialty services for CSHCN. Although NJ FamilyCare has expanded its eligibility criteria, NJ FamilyCare contracts with managed care organizations that reimburse for primary care. Obtaining referrals from HMOs for comprehensive specialty care has been reported by parents as tedious, time consuming and often too complex. Reimbursement rates for specialty care are far below the costs for services. The program continues to work with the provider agencies to improve data collection, clearly define the information that is needed from them, and establish consistency among the agencies. Some progress has been made towards mobilizing the agencies to advocate for themselves. For example, a session was held in Trenton with agency representatives from all the Child Evaluation Centers to discuss mutual areas of concern. Possible courses of action for the agencies to pursue were delineated. One goal is to document the difficulties the specialty clinics have in making services accessible and available to families. Another goal is to demonstrate the increase in referrals for certain conditions, especially in the areas of learning and behavior. The centers agreed on a revised list of disabilities/conditions to include in their quarterly reports. The reports are available for the agencies on diskettes.

Managed Care benefits packages typically recognize the services of one or two specialists who are only part of a comprehensive team of specialists required to accurately evaluate and treat CSHCN. Historically, care coordination has been provided by the sub-specialty teams collaborating with primary care providers, SCHS County Case Managers, school districts, Early Intervention Programs, DYFS, and other involved agencies. Reimbursement for team care is only a fraction of the real cost for this service.

There is dialogue between SCHEIS (Case Management) and Medicaid Managed Care. Communication is in response to the need for assisting new Medicaid clients with special needs

to self identify to Medicaid Managed Care Organizations' Special Needs Care Coordination units to access HMO Care Coordinators, Early Intervention Services, care coordination safety net for those CSHCN transitioning off Medicaid, and advocacy organizations.

Decreased availability of specialty care for CSHCN of lower income families is noteworthy in some areas. In the past decade increased numbers of children experiencing developmental problems in the areas of learning and behavior have been noted (e.g., autism and ADHD). School child study teams do not usually have the expertise to evaluate and diagnose these problems because of lack of medical and behavioral specialists. Without timely intervention, children begin a rapid cycle of educational and social difficulties which may lead to school drop-out and/or involvement with the juvenile justice system. Numbers of reports of violence and other criminal behaviors by juveniles in the school and community have increased. There is a desperate need for adequate resources for early diagnoses and development of intervention strategies.

Through a network of Child Evaluation Centers (CECs) providing comprehensive evaluations and suggested intervention strategies, attempts to enhance Child Study Team determinations are made. State funded CECs are encouraged to collaborate with school systems to promote the welfare of special needs children. However, extremely low reimbursement levels for specialty care (comprehensive team evaluation and treatment) have impacted negatively on the ability of specialty and rehabilitation care to provide quality services.

A competitive process for funding Child Evaluation Centers resulted in grant awards to eleven centers. There is limited funding for these providers and the need for services is indicated by submission of over twice as many applications as agencies receiving funding. Many of the target population for Child Evaluation Centers are those children whose needs are too complex for the school system to adequately assess and develop intervention strategies. If diagnoses are not accurate and treatment is not provided for these children, their problems will escalate quickly with sometimes disastrous results for themselves, their families, the community, and society as a whole.

In 1997, SCHEIS expanded its health service grant with the Statewide Parents Advocacy Network (SPAN) to include a Parent-to-Parent Network and to further increase the degree to which the State ensures family participation in program and policy activities in the State CSHCN program (related NPM #2). The Parent-to-Parent Network links parents of CSHCN to "veteran" parents of children with similar needs for support, information on the disability, and problem solving. The Statewide Family Voices Chapter, initiated by SCHEIS in collaboration with Family Voices and SPAN, is conducting family leadership development trainings. These trainings provide families with the information and support they need to advocate for their own children; advocate for and support other families; and advocate for improvements in policies, practices, and systems.

II.B.3.D. Cross Cutting Needs Across Population Groups

The Division of Family Health Services has developed and implemented a cultural competence training initiative. The Division's goal is to develop a seamless delivery system of culturally competent health care to the increasingly diverse citizens of New Jersey. The Division formed a Family Health Services Diversity Team that was responsible for coordination and planning for the initiative. The first step in the plan was to offer and provide health service grantees with training that specifically addresses cultural sensitivity and competency within a health care delivery system. Those organizations and agencies that are supported with grant funds have had the opportunity to send staff to a Train-the-Trainer program so that they may share what is learned with their colleagues.

Reduction of racial and ethnic disparities in health outcomes continues to be a priority in the Division of FHS with a focus on infant mortality and adolescent pregnancy. Many of the minority health report recommendations are being addressed by FHS, including a focus on cultural competency training. The NJDHSS, Division of FHS, was selected as one of five state Title V programs to participate in Targeted Technical Assistance. The National Center for Cultural Competence at the Georgetown University Center for Child and Human Development conducted the Technical Assistance as part of the Federal Maternal and Child Health Bureau Strategic Plan, with the objective of increasing the percentage of states that implement culturally

competent policies, procedures, and practices to 100%. One of the major goals identified by the group for follow-up was the development of a statewide network. The network, named the New Jersey Statewide Network for Cultural Competence (NJSNCC), has grown from eight participating organizations and agencies to nearly 30, has appointed an Executive Committee, and has in place a listserv that notifies subscribers of meetings, training and conferences, and other matters related to cultural competence. The major activity of the NJSNCC in the past year has been the development of a Web site, which is nearly complete and ready to go on line. In addition to giving information about NJSNCC and its mission, the Web site will enable individuals to subscribe to the listserv and will provide links and references to national resources on cultural competence. Its major feature, however, will be an accessible database of statewide resources in New Jersey that provide culturally competent services to individuals and other organizations.

Disparities in race and ethnicity persist across most health indicators. Variation by geography is as great as between race and ethnic groups. Variation by municipality is influenced by community factors such as poverty, socioeconomic status, and the utilization of the local health delivery system. However, complete information on the underlying contribution of poverty, low socioeconomic status, poor education, and health behaviors are lacking to untangle their effects on health measures. Future improvements in the collection of health data at the individual level are necessary to begin to separate the social influences of poverty and the community from individual influences of biology and health behavior.

Addressing the growing epidemic of obesity and overweight is a cross cutting issue that impacts across all population groups. The DHSS is building a strong foundation to move forward and develop a comprehensive state nutrition and physical activity plan. At this point, the prevention and control of obesity and other chronic diseases through nutrition and physical activity is addressed through initiatives and staff in a number of programs throughout the DHSS including activities through the DFHS, Title V programs.

Preventing obesity is critical to the health of New Jersey youth and the future of New Jersey. Childhood obesity is a lifelong threat to health and overweight children are at a heightened risk

for chronic adult diseases (eg, type 2 diabetes, hypertension, high cholesterol). Physical activity and dietary patterns, once established early in life, will often persist into adulthood. Additionally, a recent CDC study provided evidence that obese and overweight women have increased risks of having babies with heart abnormalities and other birth defects. The same study also confirmed an already reported link between pre-pregnancy obesity and neural tube birth defects including spina bifida.

II. B.4. Examine MCH Program Capacity by Pyramid Levels.

The State's capacity to meet the needs of its MCH populations by level of the MCH services pyramid is summarized in this section. Direct and enabling services are combined in section II.B.5.

II.B.4. A. Direct Health Care Services

II.B.4. B. Enabling Services

Fiscal barriers for pregnant women, mothers, infants, and children to primary care and preventive direct services have been reduced through Medicaid expansion and NJ FamilyCare. The need for enabling services will continue to be a priority even though the financial barriers for mothers, children and adolescents seeking primary health care services have been reduced. Enabling services for pregnant women, mothers and infants provided through MCCH supported programs include the Healthy Mothers/Healthy Babies programs, the Maternal and Child Health Consortia, HealthStart, and Healthy Start. Coordination efforts will continue with Medicaid and focus on implementing the NJ FamilyCare initiative and quality assurance standards for preventive and primary care services for mothers, children and adolescents.

Issues of availability of primary care services were described in the Section II.B.2 concerning the geographic distribution of primary care providers and the MCH Consortia regional planning and provider directories. Throughout New Jersey there is a good supply of dental professionals in most communities. There are approximately 7000 dentists and 4000 hygienists licensed to practice in the State. While there is a large pool of dental providers, currently less than 10% of New Jersey dentists participate to a significant level in the Medicaid Program.

New Jersey, like many other states, is concerned about the rising cost of medical malpractice insurance. In the area of maternal and child health, our greatest concern is accessibility of obstetrics and gynecology (Ob/Gyn). It has come to our attention that several OB/Gyns have stopped providing obstetric services in their practice. Access to early and regular prenatal care

for low income pregnant women is dependent on the availability of Ob/Gyns that practice in the State's underserved areas through publicly supported clinics. Additionally, with hospitals mergers/systems, consolidation of certain services including prenatal care, pediatric clinics and impatient services may reduce geographic access to care. In some cases, the closure of certain inpatient services may be appropriate if the closure it is based on a decline in the inpatient census. But in other cases the closure is to consolidate services throughout a hospital system and access is not always adequately considered. Efforts to ensure continued access to quality maternal and child health services is accomplished by Title V staff providing consultation to the DHSS' Certificate of Need Program and Hospital Licensing to assess the impact of any hospital changes being contemplated.

Improving the cultural competency of MCH direct and enabling services was addressed as well in the previous Section II.B.3 Assessment of Needs of the MCH Population Groups. Assessing numbers of health care providers does not fully address the issue of availability of care or barriers to care from the perspective of diverse communities.

There are several "emerging issues" that are challenging the state's ability to provide direct and enabling services to MCH population groups. Those "emerging issues" include oral health, post-partum depression, the state's Child Health Insurance Program, and obesity.

Under the Department's Federally Qualified Health Center Expansion Program (FQHC), the FQHCs receive cost-based reimbursement for dental health services provided to the uninsured or underinsured. Sixteen FQHCs provide dental health services. During the past year, six of the FQHCs obtained federal approval to establish a new service site or expand their scope of services to include the provision of dental health care at four additional sites located in the southern and northern regions of the State. The sixteen FQHCs provided a total of 90,104 dental health visits with approximately 42,780 of those visits for uninsured patients.

The SFY 2004 proposed budget includes several changes to the NJ Family Care (SCHIP) program. The most significant changes will impact on the low income, uninsured adult population in the State. The changes were described previously in Section III.A. NJ Family

Care will continue to outreach and enroll children into the program. Pregnant women will continue to be eligible for care through Medicaid expansion, and for undocumented pregnant women the State will continue to support prenatal care with state funding only. The funds for the state-only prenatal care program for undocumented pregnant women is limited to $3.8 million annually, with $1.9 going to hospital prenatal clinics and $1.9 going to federally designated community health centers. During SFY 2003, the funds supported services for approximately six month through hospital clinics, and nine months through the community health centers. After the special state-only funds are exhausted hospital clinics must use charity care and the community health centers are able to bill the services through the Letter of Agreement for uncompensated care.

New Jersey DHSS recognized the impact of obesity on our youth and in June 2002 convened the New Jersey Childhood Obesity Roundtable. Co-sponsors for the event were Rutgers – Department of Nutritional Sciences, the NJ Obesity Group and the First Baptist Community Development Corporation, Inc. A total of 50 stakeholders attended to generate recommendations for preventing or reducing childhood obesity in NJ. One of the key findings and its recommended solution was:
Public school nurses regularly collect student height and weight data; however, this information has not been accessible for statewide evaluation.
Conducting a retrospective statewide survey of elementary students' height and weight and calculate BMI (to establish a baseline estimate of weight status fro NJ school children)

The Departments of Health and Education collaborated to survey the weight status of younger groups than are surveyed in the Youth Risk Surveillance System. The study analyzed 2,393 sixth grade records from 40 randomly selected public schools of varying socioeconomic strata. The results showed that actual recorded weights vary from the self reported weights of high school students participating in the 2003 YRBS survey. The review of recorded weights by school nurses indicated 20% are overweight and 18% are at risk for overweight.

The Governor's Healthy Choices Healthy Kids initiative has the goal of the initiative is to improve the overall health of New Jersey's schoolchildren by improving nutritional choices in

schools, promoting greater physical activity and encouraging healthy lifestyles, including the avoidance of cigarettes, drugs and alcohol. This initiative was more thoroughly described in Section II.B.3. of this application.

In March 2003, an application was submitted to the Centers for Disease Control and Prevention (CDC) for the development of a State Nutrition and Physical Activity (N&PA) unit within the DHSS Division of Family Health Services but was not approved for funding The N&PA unit would coordinate efforts with existing Departmental programs in cardiovascular health, oral health, diabetes, cancer, maternal and child health and WIC (including breast feeding and 5 A Day). In addition, school populations would specifically be addressed by coordinating efforts with programs in the State Departments of Agriculture and Education. This level of coordination creates opportunities for increased communication resource sharing and joint planning that can result in comprehensive activities and initiatives. It also increases efficiency of workload, enhances effectiveness, minimizes duplication of services and creates synergy.

At the May 2003, New Jersey Action for Healthy Kids Summit: Taking Action for Kids Nutrition and Fitness Healthy Kids Summit. The Department of Health and Senior Services, and announced a commitment to the Governor's Healthy Kids Initiative to collaborate with the Department of Education to conduct a pilot to survey of height/weight data. A retrospective review of height/weight data of 2,393 6th grade students from 40 randomly selected New Jersey public schools of varying socioeconomic strata. The findings indicate that 38% of students were either at-risk for overweight (18%) or overweight (20%). These findings were announced at a Governors press conference in September 2004.

The fiscal barriers for CSHCN to access services have been reduced by subsidized direct specialty and subspecialty services. The CSHCN Survey and a recent national survey with Family Voices and Brandeis University have provided SCHEIS with valuable information about families' needs and experiences with health care including the kind of health coverage used, the frequency and type of service used, problems in access and coordination between agencies. The degree of change in the availability of primary care services for CSHCN with the implementation of NJ FamilyCare and Medicaid Managed Care is uncertain. Since a number of children

receiving services through county case management units still have difficulty accessing health care services and are ineligible for FamilyCare and Medicaid due to income eligibility, SCHEIS will maintain its safety net of direct specialty services for CSHCN through its network of providers. The County Case Management Units will continue to assist families in identifying financial and insurance resources while providing referrals to primary care and specialty services.

Ongoing efforts are made by SCHEIS to support agencies providing direct specialty and sub-specialty services for CSHCN. Although NJ FamilyCare has expanded its eligibility criteria, NJ FamilyCare contracts with managed care organizations that reimburse for primary care. Obtaining referrals from HMOs for comprehensive specialty care has been reported by parents as tedious, time consuming and often too complex. Reimbursement rates for specialty care are far below the costs for services. The program continues to work with the provider agencies to improve data collection, clearly define the information that is needed from them, and establish consistency among the agencies. Some progress has been made towards mobilizing the agencies to advocate for themselves.

Improvements in the reporting and tracking of newborn screening programs are evident in the Newborn Biochemical Screening Program and the Early Hearing Detection and Intervention Program. New Jersey birthing facilities must establish guidelines for follow-up for newborns identified with or at risk for developing hearing loss. Follow-up services must include but are not limited to: 1) confirmatory pediatric audiological assessment, 2) diagnosis of newborns with abnormal or inconclusive test results, 3) submissions of Newborn Hearing Follow-up Report, 4) counseling and educational services for parents, guardians or custodians, 5) explanation of potential effects of hearing loss on development of speech, language, and/or cognitive skills, 6) potential benefits of early identification and intervention.

II.B.4.C. Population-Based Services

The essential population-based services provided by the State are the Newborn Biochemical Screening, Lead Screening, Newborn Hearing Screening, and Immunizations Programs. Other population-based services are the SIDS Center of New Jersey, the Black Infants Better Survival

awareness campaign, injury prevention programs, physical fitness and nutrition programs, the school fluoride mouth rinse program, and oral health education programs.

In the area of Newborn Biochemical Screening, additional screening tests have been added to the screening panel. Testing, reporting and follow-up are all directly managed by the State and are available statewide. As genetic tests are perfected, it will be possible to screen for more newborn biochemical disorders. Since there are no national standards concerning which disorders to include in a screening panel, states are faced with balancing the new technologies into the system of newborn screening. More than just laboratory tests, the system must be able to follow, treat, and influence clinical outcomes. To address these changes and concerns, a Newborn Screening Annual Review Committee reconvened in March 2005 and serves to advise the Newborn Biochemical Screening Program.

In 2004, 98.8% of newborns were screened for hearing loss prior to hospital discharge. The number of newborns receiving hearing screening continues to increase as more hospitals adopt universal screening policies. Amended regulations took effect in 2002, require all birthing facilities to screen all newborns prior to discharge or before one month of age. Newborns identified with hearing loss are registered with the Special Child Health Services Registry and referrals within ten days are made to the County Based Case Management System. Newborns identified with hearing loss are registered with the Special Child Health Services Registry and referrals within ten days are made to the County Case Management Units. The case management system serves as a single point of entry into the Early Intervention System. Any level of hearing loss provides presumptive eligibility into the Early Intervention System.

DHSS maintains a childhood lead poisoning surveillance to receive blood lead reports from laboratories and to notify local health departments who are required to follow-up individual children. As of July 1999, laboratories are required to report all blood level tests to the DHSS. Universal lead testing reporting will provide accurate local assessment of lead poisoning and permit targeted prevention activities. Further collaboration with local organizations such as the Newark Partnership for Lead Safe Children will be needed to move from identification and treatment of lead poisoned children to primary prevention of lead poisoning. DHSS received

additional funding from CDC for 2003-2004 to support primary prevention activities in Newark, Irvington and Camden.

The New Jersey State Immunization Information System (NJSIIS) is an electronic repository of information on the immunization status of children, designed to improve immunization tracking and increase immunization rates. The system has been installed at 99 sites and is currently being expanded. The expansion is being facilitated by the regional Maternal and Child Health Consortia (MCHC). Each of the MCHCs has received support from the Immunization Program to increase provider participation in the registry. The MCHCs will be identifying large pediatric providers within their respective regions, providing educational and outreach programs to promote registry participation and serve as a local resource for technical assistance. The Immunization Program in the Division of Communicable Diseases supports population-based services through NJIIS, annual immunization surveys, providing technical assistance to local health departments and schools, implementing the Vaccine For Children Program, and providing vaccines to public sector providers. Further use of population-based data, identification of barriers to complete immunization, and reduction of missed opportunities to immunize are needed to increase existing immunization rates. Arrangements have been made to link the childhood lead poisoning surveillance system with NJIIS. This will enable participating primary care providers to access both immunization and lead screening status of children in their care.

FHS has recognized and responded to the need for statewide population-based educational services such as the SIDS Center of New Jersey and the Black Infants Better Survival (BIBS) campaign. Information on FHS programs as well as referral services to MCCH programs is available statewide through the toll-free Family Health Line telephone. The need for local population-based services such as oral health education programs, school fluoride mouth rinse programs, and injury prevention programs has already been described in Section II.B.3 Assessment of Needs of the MCH Population Groups. FHS will expand those population-based programs and other model programs which have been shown to be effective.

II.B.4.D. Infrastructure Building Services

FHS promotes comprehensive systems of services for the MCH population by continually assessing statewide needs, identifying priority needs, developing strategic plans, collaborating with other agencies and allocating resources to meet targets. Existing systems and collaborative mechanisms for all three MCH population groups are assessed at the state and regional levels. The State's efforts to promote infrastructure building services and to promote comprehensive systems of services are diverse and quite dynamic. Instead of providing details here every five years in this Needs Assessment section, the State's activities will be presented annually in the appropriate application sections related to State Agency Coordination, State Priorities, National Performance Measures, and State Performance Measures.

Collaborative efforts to promote comprehensive systems of care will be updated annually in Section II.B. State Agency Coordination. Coordination efforts include lead poisoning, immunizations, oral health, and injury prevention.

The Maternal and Child Health Consortia (MCHC) were developed by the NJDHSS to promote the infrastructure and delivery of the highest quality of care to all pregnant women and newborns; to maximize utilization of highly trained perinatal personnel and intensive care facilities, and to promote a coordinated and cooperative prevention-oriented approach to perinatal services. Continuous quality improvement activities are coordinated on the regional level by the MCHC. The MCHC regional plans now include pediatric need assessments and an inventory of resources including directories of providers.

The FHS maintains several population-based MCH related surveillance systems, including Childhood Lead Poisoning, Birth Defects Registry, Special Needs Registry, Iniversal Newborn Hearing Screening Registry and the Electronic Birth Certificate. MCH Epi currently links the available EBC, hospital discharge, death certificate and Medicaid files to enhance its surveillance and research activities. These file linkage functions are supported by the SSDI grant. FHS was funded by the CDC to implement a Pregnancy Risk Assessment Monitoring Survey (PRAMS)

survey starting in October of 2002. PRAMS will provide valuable information for the planning and evaluation of perinatal programs.

The New Jersey Fetal Infant Mortality Review and New Jersey Maternal Mortality Review processes are infrastructure building services that promote comprehensive systems of services. Information collected from these review processes, including data and issues identified by the Case Review Team, will be analyzed and used in the need assessment process at the State level for program planning and policy development. Region-specific findings from the review process will be provided to the MCH Consortia to be utilized in their continuous quality improvement activities and for utilization by their member hospitals for quality assurance activities.

Coordination efforts also occur with organizations that are separate from Title V programs, but intricately involved with the populations served by Title V. As previously noted, WIC, Early Intervention Services under Part C of the Individuals with Disabilities Education Act, Ryan White Title IV, Primary Care Cooperative Agreement, and numerous Center for Disease Control and Prevention programs (asthma, childhood lead poisoning, hearing screening, PRAMS, etc) are all administered through the Division of Family Health Services leading to a more coordinated approach to services for the population. Coordination with other governmental agencies in the areas of quality child care, child protection, school based health services, curriculum development, developmental disabilities is evidenced by Title V participation on numerous Councils, Task Forces, or committees. As examples of extended coordination Title V staff participate on:

Interdepartmental School Age Health Committee (Coordinated School Health Program)
New Jersey Task Force on Child Abuse and Neglect
Developmental Disabilities Council
Domestic Violence Task Force
Special Education Advisory Council
Healthy Child Care America Committee
Professional Development Center Advisory Board (early child care/education)
Oral Health Coalition
Pedestrian and Bicycle Task Force

Governor's Council on Alcoholism and Drug Abuse
Promoting Safe and Stable Families

A priority for SCHEIS is ensuring rehabilitative services for blind and disabled individuals less than 16 years old receiving services under Title XIX. SCHEIS receives monthly printouts from the Social Security Disability Determination Unit that identify all children applying for Social Security Insurance (SSI). Copies of the printouts are sent to the appropriate County Case Management Units. County Case Management Units outreach to all SSI applicants to offer information, referral, and case management services. SCHEIS is collaborating with Medicaid to identify through the Birth Defects Registry any child who may have special health care needs but is not on SSI. This is in order to ensure that the child and their family have access to any special services that would otherwise be available to that population, including case management services.

In New Jersey, the Ryan White Title IV program is operational under the administrative auspices of the Department of Health, Division of Family Health Services, Special Child, Health and Early Intervention Services. The program has been strategically placed within this Division/Unit in order to provide a close link with Title V agency operations and to maximize the utilization of MCH resources available for women, infants, youth and families in the state. In addition to MCH staff representation on the Title IV Network Executive Advisory Committee, a close working relationship with co-located programs including Family Planning, prenatal services and high risk clinics, WIC, federally qualified health centers and Healthstart has been ongoing since the inception of the program in 1988. At the local level, Ryan White Title IV Network agencies have established formal linkages with community based MCH resources to ensure the availability of comprehensive services for women and children.

The Family Centered Care Services', Case Management unit assists families to access family centered, comprehensive, coordinated, culturally competent, community based services for their children with special health care needs. Formal and informal linkages ensure collaboration between Title V, Title IV, Title XIX, IDEA Part C, Local Boards of Chosen Freeholders and other State, federal and community based agencies. State statute requires the reporting of

children with birth defects to the Birth Defects Registry, and subsequent referral to case management units for follow-up. Likewise, an interagency memorandum of agreement between the Department of Health and Senior Services and the Department of Human Services facilitates referral and follow-up of SSI eligible CSHCN. Letters of agreement between the Department of Health and Senior Services, Local Boards of Chosen Freeholders and community-based agencies mandate funding for the provision of case management services. Contractual language in county case management health service grants defines programmatic requirements, including Part C service coordination and Title V case management collaboration. Each case management unit maintains a letter of agreement with the Department of Human Services to case manage CSHCN enrolled in Medicaid model waiver programs. In addition, informal linkages include networking between State staff, county case managers, and community based agencies such as the Elks, Kelly Ann Dolan Foundation, Shriners' Hospital, and other social service agencies to assist in maintaining CSHCN in their communities.

Existing systems and collaborative mechanisms to comprehensively address school health issues are discussed in Section II.B.3 concerning Child and Adolescent Health Programs involvement with school-based youth services, the Community Partnerships for Healthy Adolescents. New Jersey's Action for Healthy Kids (AFHK), the Governors Healthy choices, Healthy Kids initiative and Interdepartmental Committee on School Age Health. A retreat in January 2004 brought together key staff from the DHSS, DOE and Department of Human Services (DHS) for the purpose of assessing progress in the implementation of the Strategic Plan for School Age Health and , 2) updating the plan to reflect current needs and priorities. However, with in a few months of retreat date, the State was notified of an upcoming training opportunity scheduled to take place in September 2004: Coordinated School Health Program (CSHP): Achievement Through Partnerships. The training was sponsored by the Association of State and Territorial Chronic Disease Program Directors (Chronic Disease Directors-CDD), the Association of State and Territorial Directors of Health Promotion and Public Health Education (Directors of Health Promotion and Education – DHPE), and the Society of State Directors of Health, Physical Education and Recreation (SSDHPER) and focused on establishing State – level collaborative efforts for the CSHP model. Five New Jersey team members representing the Department of Health and Senior Services and the Department of Education were designated to participate in

this training. By doing so, New Jersey would be more favorable positioned to apply for CDC infrastructure funds when that opportunity arises.

A meeting was held with DHSS and DOE administration in December 2004 at which time a commitment to the CSHP model was expressed by both Departments. It appears likely that the existing structure of the interdepartmental Committee on School Age Health (ICSAH) would be reorganized to fit the eight component CSHP model. This model would provide the framework for identifying and coordinating school health activities/programs/services that are both currently provided as well as those needed. A joint statement already exists between the two Departments as well as the Department of Human Services (DHS) as a result of the collaborative work accomplished by ICSAH.

In January 2005, there was a follow-up conference call between the sponsors of the September 2004 training and NJ State Team members. Progress on the action plan developed at the training was discussed. Meanwhile, contact has been made with individuals who have programs or services involved in school health and an intradepartmental meeting was held in February 2005. The purpose of the meeting was to build relationships and improve intradepartmental communications; identify existing resources (programs/services) so that a "Resource Guide to School Health Programs" can be developed; identify a plan for marketing the adoption the CSHP model across all State Departments; and, strengthen the joint statement between the Departments by establishing an interdepartmental memorandum of understanding (MOU) that would outline the roles and responsibilities of each Department. The intent of the MOU would be institutionalize a CSHP within the current structure of the New Jersey state government. In other words, create infrastructure capacity for CSHP.

Health and education are joined in fundamental ways with each other and with New Jersey's children. Cooperative efforts among New Jersey's Department of Health and Senior Services, Education and Human Services support comprehensive school age health education and related health services and programs. Given the diverse health related program and regulatory concerns that span the departments, there is a commitment to provide policy direction and guidance on comprehensive school age health education through the development of a shared vision and

goals. The three Departments established the Interdepartmental Committee on School Age Health in 1999 and in 2000 developed the New Jersey Joint Statement on School Age Health and Strategic Planning. In addition, DHSS and the Department of Education have designated staff that serve as liaisons to the respective Departments and work with a variety of agencies and organizations, including the New Jersey State School Nurses Association, to improve the health of school age children.

Coordination of efforts with the WIC program is discussed with multiple sections concerning breastfeeding nutrition education and literacy. WIC funds breastfeeding promotion activities through grants to 14 local WIC agencies and 5 MCH Consortia.

Collaborative efforts with other major providers of health and health-related services are described in Section III.E. State Agency Coordination. Regional efforts to promote comprehensive systems of services for the three MCH populations are coordinated regionally by the six MCH Consortia as described in Section III.E. Other examples include the NJ Chapter of the American Academy of Pediatrics, NJ Chapter of the March of Dimes, the Parent-to-Parent Network of the Statewide Parents Advocacy Network for CSHCN, the NJ Chapter of Family Voices. Family Practice, dentists, and parent groups.

The Department collaborates with various other State agencies and private organizations to promote a comprehensive system of services of its CSHCN populations. SCHEIS works with parent groups, specialty providers and a statewide network of case managers to provide family-centered, community-based, coordinated care for CSHCN. SCHEIS collaboration with other agencies is described in Section III.E. State Agency Coordination. Recent issues concerning managed care and CSHCN have brought together the Office of Managed Care in DHS, parents, advocate groups, and HMO case managers to assist CSHCN families navigate the managed care system.

In the area of quality of care FHS has recognized the need to promote standards of care in a number of areas including lead assessment and treatment, subspecialty services of CSHCN, and comprehensive perinatal care guidelines for Health Start services. The future development of

standards of care in specific clinical areas will be appropriately addressed by expert advisory groups.

II.B.5. Selection of State Priority Needs

The selection of the state's eight priority needs is a product of FHS's continuous needs assessment. Influenced by the departmental budget process, the MCH Block Grants needs assessment process and the collaborative process with other MCH partners, FHS has selected the eight priorities listed in Section IV.B. State Priorities. Some of these priorities have been longstanding priorities (SP #2 Decreasing Black Infant Mortality, SP #3 Decreasing Teen Pregnancy, SP #7 Improving and Integrating Information Systems, and SP #8 Improving Access to Quality Care for CSHCN). Others are priorities that broadly address several issues (SP #1 Decrease Adolescent Risk Taking Behaviors and SP #4 Increase Healthy Births). The remaining two priorities focus attention on more recent public health issues (SP #5 Improving Nutrition and Physical Fitness, and SP #6 Decreasing Asthma Hospitalizations).

The Reduction of Adolescent Risk Taking Behaviors (SP #1) addresses several adolescent health issues and relates to National Performance Measures (NPM) #8, 10, 13, 16 and State Performance Measures (SPM) #5, 6 & 10. DHSS funds Community Partnerships for Healthy Adolescents in eight communities. The purpose of these Partnerships is to coordinate the work of local health departments, community-based organizations and health care providers in reducing risk-taking behaviors and promoting healthy behaviors among adolescents. Each Partnership's activities are based on a local needs assessment that identified what are the priority adolescent health issues in that community. It then develops an Adolescent Health Plan to address these issues. DHSS guidelines encourage the Partnerships to address sexual behaviors, injury prevention, and nutrition and physical activity.

Reducing Black Infant Mortality (SP #2) is a state priority related to NPM #15, 17 & 18 and SPM #1 & 3. The Northern New Jersey MCH Consortium has been funded to serve as the Black Infant Mortality Reduction (BIMR) Resource Center under the Black Infant Mortality Reduction Initiative since July 1999. The Center is designed to provide technical support to programs and information to professionals with an interest in improving maternal and infant health in black families. Seven health service grants addressing black infant mortality reduction, totaling one million dollars were awarded in June 2000 to health service agencies and grassroot organizations statewide.

Reducing Teen Pregnancy (SP #4) is a state priority for New Jersey and relates to NPM #8 (reduction of births to teens 15-17 years of age) and SPM #4 (percent of repeat pregnancies among adolescents 15-19 years of age). The Advisory Council on Adolescent Pregnancy Prevention was established in 1999 to develop policy proposals, to promote a coordinated and comprehensive approach to the problems of adolescent pregnancy and parenting, and to promote community input and communication. In 2003, the Council developed a three-year strategic plan to guide the work of the Council and focus on specific areas of interest. The WorkFirst Teen Pregnancy Prevention Work Group lead by the Department of Human Services has been charged with planning, developing and implementing new initiatives. Youth-to-youth programs and mentoring projects and a Teen Pregnancy Resource Center have been established. The Department of Human Services, the Department of Education, the Department of Labor and the Juvenile Justice Commission have collaborated with NJDHSS on the development of statewide County Collaborative Coalitions relative to teen pregnancy prevention activities.

Family planning agencies with 60 clinical sites continue to provide comprehensive reproductive health services to adolescents. Family planning agencies also provided community education and outreach to the adolescent population. Aimed at schools and community groups, educational activities focus on primary pregnancy prevention activities that encourage family communication, promoting self-esteem, postponing sexual activity and promoting effective contraception. The program integrates assessment of adolescent risk behavior within routine family planning services.

The percent of repeat births among adolescents 15-19 years of age (SPM # 5) is a priority because teen parents are more likely to have another child within two years, often leading to increased hardship and economic dependency.

Increasing Healthy Births (SP #4) is a state priority that encompasses NPM #8, 15, 17, 18 and SPM #1, 3, 5, 8, 9. Several initiatives in the Perinatal Health Services Program address healthy births including Healthy Mothers, Healthy Babies Coalition outreach activities, Healthy Start outreach activities, and Community action team projects based on FIMR findings. The Perinatal

Addictions projects seek to educate professionals and consumers of the risks involved with substance use and abuse in the perinatal period. Preconceptual health projects seek to have a healthy mother prior to conception.

Improving Nutrition and Physical Fitness (SP #5) is a state priority related to SPM # 10 and the new Health System Capacity Indicator (HSCI) #9. Our goal is to prevent and control obesity and other chronic diseases by developing and implementing best practices and/or evidence-based nutrition and physical activity interventions. DHSS funds Community Partnerships for Healthy Adolescents in eight communities. The purpose of these Partnerships is to coordinate the work of local health departments, community-based organizations and health care providers in reducing risk-taking behaviors and promoting healthy behaviors among adolescents. DHSS staff work with three Partnerships to address nutrition and physical activity as a priority adolescent health issue. The Governors Healthy Choices Healthy Kids initiative brings together three state agencies to address this state performance measure. State law has established a New Jersey Council on Fitness and Sports. DHSS provides staff support to the Council. At the New Jersey Action for Healthy Kids Summit: held in May 2003 the Department of Health and Senior Services, Education and Agriculture announced their joint commitments for the next year to the Governor's Healthy Choices, Healthy Kids Initiative. Since this Summit, the DHSS commitment to conduct a retrospective review of height/weight collaboration with the Department of Education data of nearly 2400 6th grade students was completed. Students' health records were obtained from 40 randomly selected New Jersey schools of varying socioeconomic strata. In March 2003, an application was submitted to the Centers for Disease Control and Prevention (CDC) for the development of a State Nutrition and Physical Activity (N&PA) unit within the Department of Health and Senior Services, Division of Family Health Services. The application was not approved for funding.

Decreasing Asthma Hospitalizations in Children (SP #6) is related to NPM #7, 13 and SPM #6 and 14. DHSS is a member of the Pediatric/Asthma Coalition of New Jersey (PAC/NJ). PAC/NJ is organized by the American Lung Association of New Jersey and the New Jersey Thoracic Society. It has developed a Strategic Plan to address asthma in New Jersey, and has formed six task forces to develop and implement activities to achieve the objectives of the Plan.

In 2002, the DHSS formed an Interdepartmental Working Group on Asthma. With the participation of staff from the Departments of Education, Human Services, and Environmental Protection, the working group prepared a strategic plan for the activities of New Jersey State Government in addressing asthma. A federal CDC grant funded the creation of a full-time asthma epidemiologist in the MCH Epidemiology Program to develop an asthma surveillance system in New Jersey. The first product of this system is the report, *Asthma in New Jersey,* published in February 2003.

The New Jersey Special Child Health Services Registry allows for the voluntary reporting of asthma as a chronic condition in children. Children registered are referred to the Family Centered Care Program, which provides case management assistance to the families through the county-based Special Child Health Services case management programs.

The MCH Epidemiology Program, the Division of Family Health Services, and the NJDHSS are all involved in efforts to improve and integrate public health information systems (SPM #7). Activities are related to NPM #1, 12 and HSCI #5, 9A, 9B, and 9C. Examples of improving access to and integration of public health information are discussed in sections specific to the performance measures and health systems capacity indicators.

New Jersey will enhance current efforts to improve access to quality of care for CSHCN (SPM #8), as well as provide additional training opportunities for families, case managers, Part C service coordinators and staff of the Child Evaluation Centers, Cleft Lip/Palate Centers, Tertiary Care Centers, and Ryan White Title IV Family Centered HIV grantees in resources and services to support CSHCN in the community. Training will be provided to promote effective involvement of youth and parents in school to work transition, and medical transition to adulthood for the SSI population.

II.C. Executive Summary

The completion of a comprehensive needs assessment for the MCH population groups is a continual process that the Division of Family Health Services performs in collaboration with a number of other organizations. The overall needs assessment methodology is similar for each of the three population groups - preventive and primary care services for pregnant women, mothers and infants; preventive and primary care services for children; and services for children with special health care needs.

The annual State budget process includes several steps that are very similar to the stages and functions to the MCH block grant needs assessment. In preparation for the annual State budget hearings where the department's budget priorities are presented to the Governor and legislature, FHS reviews and summarizes programmatic activities, service capacity, budgets, and emerging issues. Activities, budgets and priorities are justified in terms of standard health indicators and program evaluation data. This annual several month process takes place at the program level, the division level, then the department level, and finally is presented to the Governor and in turn the legislature. The annual State budget process overlaps with the MCH needs assessment process beginning in October and ending in April.

Advisory groups and task forces provide valuable expert input, public and private constituency representation, and family member involvement into the MCH needs assessment process. Examples of key MCH advisory groups and task forces include: NJ Interagency Task Force on the Prevention of Lead Poisoning, Advisory Council on Adolescent Pregnancy, Medicaid Managed Care Alliance, New Jersey Council on Physical Fitness and Sports, NJ obesity Prevention Task Force Newborn Screening Annual Review Committee and the Statewide Parent Advocacy Network (SPAN) for CSHCN. Other detailed descriptions of collaborative processes and partnerships with the public and private sector and other state and local levels of government are included in Section III.E. State Agency Coordination.

At the regional level the MCH Consortia conduct planning and needs assessment to promote a coordinated prevention-oriented approach to MCH services. Through regulations, each MCH

Consortium must submit to the NJDHSS a regional perinatal and pediatric plan for approval, with projections for the following three years. The regional plans must address pediatric morbidity and mortality, risk-appropriate prenatal care, low birth weight, and teen births. The social, cultural, economic and demographic factors influencing the perinatal and pediatric needs of their communities must also be described. These plans serve as a guide for the MCH Consortium and its members in the development, coordination and evaluation of services for pregnant women, infants, children, and adolescents in the communities they serve.

The grant awarding, renewal and monitoring processes continually assess local needs that are specific to geographic areas. FHS funds numerous grantees involved with MCH programs on a regional or local level. The selection process includes a review of local identified need. Renewal and monitoring of grantees is based on measurable outcomes that are designed to address identified needs. Many of the agencies that are awarded health services grants by FHS use the MCH Block Grant performance measures or Healthy People 2010 objectives as their outcome measures. Examples of local grants include case management to assist primary health care providers through PORsCHE, and local planning and perinatal outreach through HM/HB Coalitions.

The quantitative surveillance and analysis of MCH data by the MCH Epidemiology Program provide continuous input into the needs assessment process. The MCH Epidemiology Program produces standardized MCH health indicator reports for FHS, for the MCH Consortia, and for other public health related organizations by special request. The MCH Epidemiology Program works with the Vital Statistics Program, the Center for Health Statistics, other departments in NJDHSS, and the MCH Consortia Data/TQI Workgroup to support data needs for regional planning. The MCH Epidemiology Program also conducts applied research projects which currently focus on issues related to breastfeeding, smoking and pregnancy, prenatal care utilization, identification of risk factors for adverse birth outcomes, childhood asthma and longitudinal birth histories.

Public comment on regulations and publications is an ongoing process of needs assessment and input from both public and private constituents. Rules implementing laws sunset every five

years, and therefore, programs must readopt rules every five years. Proposed rules are published in the New Jersey Registry (NJR) with a 60-day open comment period. Responses to all public comment must be published, along with possible changes to the proposal before adoption of the rules (also published in the NJR). Public comment on the development of the MCH Block Grant application is also encouraged through a public hearing on the MCH Block grant held annually in May. A draft of the narrative is posted to the Department's website four weeks prior to the public hearing.

The selection of the state's eight priority needs are a product of FHS's continuous needs assessment. Influenced by the departmental budget process, the MCH Block Grants needs assessment process and the collaborative process with other MCH partners, FHS has selected the eight priorities listed in Section IV.B. State Priorities. Some of these priorities have been longstanding priorities (SP #2 Decreasing Black Infant Mortality , SP #3 Decreasing Teen Pregnancy, SP #7 Improving and Integrating Information Systems, and SP #8 Improving Access to Quality Care for CSHCN). Others are priorities that broadly address several issues (SP #1 Decrease Adolescent Risk Taking and SP #4 Increase Healthy Births). The remaining two priorities focus attention on more recent public health issues (SP #5 Improving Nutrition and Physical Fitness, and SP #6 Decreasing Asthma Hospitalizations).

II.D. Health Status Indicators

The former guidance for the MCH Block Grant specified a set of "core health status" indicators, which were required to be reported each year. New Jersey has used the core health status indicators to monitor its progress in improving or maintaining the primary care infrastructure. These "core health status" indicators (formerly core health status indicators #1, #2, #3, #6 and #7) and one developmental health status indicator (#4) are now referred to as "health systems capacity" indicators. These "health systems capacity" indicators will be reported annually. In addition to the original 'core' health status indicators, the former guidance specified a set of 10 'developmental' health status indicators of which 5 were demographic information specific to each State. The rationale for the 'developmental' health status indicators was that they would "provide additional data that the MCH Bureau had determined to be important. New Jersey regards the developmental health status indicators, now referred to simply as "health status indicators," as some of the many factors that will be considered when preparing its annual report and Five Year Statewide Needs Assessment. The Health Status Indicators are reported in Health Status Indicator Forms 20 – 21 in Appendix B.

II.E. Outcome Measures - Federal and State

The MCH outcome measures enumerate the final desired result of program activities undertaken to achieve MCH objectives. Outcome measures are longer term goals than specific performance measures goals and outcome measures can often be attributed to a number of influences and various program activities. It is recognized that there are numerous and varied factors that influence outcome measures, some of which are outside the control of Title V programs. This section provides a brief discussion on the relationship between State program activities, the national and state performance measures, health system capacity indicators, health status indicators, and the outcome measures.

Table 6	***National Performance Measure***	***State Performance Measure***	***Health Systems Capacity Indicator***	***Health Status Indicator***
1) The infant mortality rate per 1,000 live births.	1, 11, 15, 17, 18	*1, 2*	*4, 5, 9A*	*1A&B, 2B, 8A*
2) The ratio of the black infant mortality rate to the white	15, 17, 18	*1, 2*	*4, 5, 9A*	*1A&B, 2B, 8A*

infant mortality rate.				
3) The neonatal mortality rate per 1,000 live births.	15, 17, 18	*1, 2*	*4, 5, 9A*	*1A&B, 2B, 8A*
4) The postneonatal mortality rate per 1,000 live births.	15, 17, 18	*1, 2*	*4, 5, 9A*	*1A&B, 2B, 8A*
5) The perinatal mortality rate per 1,000 live births.	15, 17, 18	*1, 2, 8*	*4, 5, 9A*	*1A&B, 2B, 8A*
6) The child death rate per 100,000 children aged 1-14.	*7, 10*	*5*	*1*	*3A&B, 4A&B, 8A*
7) The fetal mortality rate per 1,000 live births plus fetal deaths.			*4, 9A*	

OM #1) The infant mortality rate per 1,000 live births.
OM #3) The neonatal mortality rate per 1,000 live births.
OM #4) The postneonatal mortality rate per 1,000 live births.

The MCH program activities that impact on infant mortality (OM #1, 3 & 4) occur through several national and state performance measures, health systems capacity indicators and health status indicators (see Table 6). These program activities address most recognized risk factors for infant mortality and involve all levels of the MCH services pyramid. Major activities by national and state performance measures are summarized in Figure 4a and 4b.

Infant Mortality Rates (IMR) have declined significantly in New Jersey since 1990. The greatest decline in infant mortality has occurred in early neonatal mortality (Chart 8 & 9). It is widely believed that this decline in early neonatal mortality is due to improvements in the management of very low birth weight and premature infants through new technology related to ventilators, surfactant, parental nutrition, and infection control. New Jersey is very proud of the regional perinatal system that has been developed with the MCH Consortia. Although it is difficult to attribute general program activities to individual level outcome measures, performance measure # 17 indicates that more high risk infants are being delivered at the appropriate perinatal hospital designation level. The Division and the MCH Consortia have worked on activities concerning referral agreements, transportation guidelines, and professional education to support the regional perinatal system.

LBW greatly influences infant mortality. New Jersey has several important activities addressing the risk factors for LBW, VLBW and prematurity. The MCH Consortia's efforts to improve risk

appropriate services for high risk newborns through a regional perinatal system are discussed above. Referral agreements, transportation guidelines, quality assurance teams at the hospital level, and local FIMR teams are all involved with promoting appropriate services for the high risk mother, fetus, and infant. More recently efforts have been placed on preconceptual initiatives that could improve a women's health and pregnancy outcome before she becomes pregnant.

The regional MCH Consortia and municipal Healthy Mother / Healthy Babies (HMHB) Coalitions are very involved with targeting services to the highest risk populations were the recognized risk factors for infant mortality are most prevalent. Efforts to improve early and appropriate prenatal care utilization through initiatives like Healthy Start and HMHB have improved in certain municipalities. Efforts to address the more difficult measures of risk such as poverty, lack of education, stress and other psychosocial variables need more attention.

Birth Defects are a leading cause of infant mortality in New Jersey and there are several initiatives to reduce their burden on infant neonatal and post-neonatal mortality. Efforts are underway to reduce risk factors for specific birth defects (folic acid and FAS) and several research efforts are underway to identify preventable birth defects. The introduction of new newborn biochemical screening tests through tandem mass spectometry has greatly improved the ability to identify life threatening biochemical disorders and prevent treatable conditions.

OM #2) The ratio of the black infant mortality rate to the white infant mortality rate.

Race and ethnic differences in IMR (OM #2) remain a major concern (Chart 10). Although all race/ethnic groups have experienced declines in IMR, the relative difference in rates between black non-Hispanic and white non-Hispanic newborns, expressed as the ratio of black to white IMRs, remains at 3.8 for 2002 data. The HMHB Coalitions target the eleven cities with the highest infant mortality rates, low birth weight rates, and inadequate prenatal care rates. Four federally funded Healthy Start projects exist in Camden, Atlantic City, Trenton and East Orange. The Black Infant Mortality Reduction initiative target this disparity in infant mortality rates

through public awareness campaigns, a provider education component and local health service grants.

OM #7) The fetal mortality rate per 1,000 live births plus fetal deaths.
OM #5) The perinatal mortality rate per 1,000 live births.

Fetal mortality (OM #5 & 7) is an issue that is receiving more attention as the number of fetal deaths exceeds the number of infant deaths. Fetal mortality has declined over the last decade, but how appear to have leveled off. As the threshold of viability is pushed lower and lower the distinction between late fetal and early neonatal deaths become blurred. The early gestational age of many fetal deaths raise the question of the appropriateness of emphasizing interventions that occur during prenatal care and only begin once the mother enters prenatal care. More appropriate preconceptual and women's health issues need to be addressed by the programmatic activities as discussed in Section IV. Priorities, Performance, and Program Activities. Improving our understanding and identifying specific causes of fetal death and risk factors for fetal death are being examined by the Fetal Birth Defects Registry and research projects by the MCH Epidemiology Program. Systems issues are being examined by the local FIMR teams.

OM #6) The child death rate per 100,000 children aged 1-14.

Several performance measures and many state program activities are directed toward reducing the child death rate. By far the leading cause of death for children is unintentional injuries, mainly motor vehicle accidents (MVAs). New Jersey has increased its activities and collaboration related to injuries as demonstrated in Section II.B.3. Assessment of Needs of the MCH Population Groups. Clearly community based programs are necessary to sustain local partnerships and efforts. Birth defects and congenital anomalies contribute to the child death rate and were discussed earlier in this section. Increasing resources and collaboration are going into Child Fatality Review, as described in Section III.E. State Agency Coordination, to identify prevention initiatives and to generate system changes. Causes of death outside the control of Title V programs such as cancers and homicides are challenges toward which increased collaborations can be documented.